

## **Appendix 1 How to Use this Document**

### ***Purpose of the Epidemiologic Profile***

The purpose of the Epidemiologic Profile is to provide information on the Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) epidemic for use in the planning of activities to prevent the spread of HIV, for planning services to people infected with HIV and those diagnosed with AIDS, and to inform policies and programmatic developments, both at the state and local levels, as they pertain to HIV/AIDS prevention and treatment. As such, the target audience for this report includes medical and social service providers, policy makers and advocates, and other people with baseline knowledge of HIV/AIDS.

This appendix of the Epidemiologic Profile describes how to use this document. It includes an overview of the organization of the document, a description of what the Epidemiologic Profile can be used for, and a description of the data sources used and their limitations. A glossary of commonly used epidemiologic terms and acronyms can also be found in the appendices.

### ***Organization of the Epidemiologic Profile: Eight key questions***

The Epidemiologic Profile is organized with a question and answer format, with each chapter addressing one key question. In total there are eight chapters and therefore eight questions:

- 1- Who is most at risk of HIV infection?
- 2- How have patterns of HIV infection changed over time?
- 3- Who is infected but does not yet know it?
- 4- Who is currently living with HIV/AIDS?
- 5- Who is experiencing differential impact from HIV/AIDS?
- 6- How have patterns of AIDS diagnoses changed over time?
- 7- Who is dying of HIV/AIDS and how has this changed over time?
- 8- What is the profile of HIV positive people who use publicly funded services?
- 9- What is the geographic distribution of people living with HIV/AIDS in Massachusetts?

## ***Guidelines for the Use of Information***

HIV and AIDS case surveillance is the primary source of the data presented in this report. HIV and AIDS case surveillance data only represent people who have been diagnosed with HIV or AIDS and for whom a case report was submitted to the HIV/AIDS Surveillance Program of the Massachusetts Department of Public Health by a health care provider. Some people have tested positive, but have not yet seen a health care provider while others may be infected with HIV, but have yet to be tested. In order to provide a broad view of the epidemic and to understand more fully which populations are at greatest risk, a variety of data sources have been used in this document in addition to HIV and AIDS surveillance data. These data sets have unique strengths and limitations depending on whether the data are self reported by the infected individual, the comfort of individuals to report personal behaviors, the willingness of providers to ask about risk history, and the documentation of accurate information in the medical record. Interpretation of any information in this document should be made in the context of the particular data source from which the statistics were derived.

Below are some general guidelines for interpretation of the data contained in this document. (These were adapted with permission from the Texas Department of Health). The section that follows, titled "Description of Data Sources", provides answers to the questions posed below. Finally, a table is included which summarizes the strengths and weaknesses of each data source.

### **1. Understand what you are looking at**

- What does the information cover?
- Does it represent HIV that never progressed to AIDS or AIDS cases?
- Do the numbers represent new cases or cumulative numbers?

### **2. Know the limitations of the information sources**

- How complete are the data?
- Does the information represent the general population or just a select subgroup?

### **3. Don't over-interpret the information**

- Increases or decreases in small numbers are magnified when calculated on a proportional basis.
- Numbers fluctuate - a one-time variation may represent a trend or may just be a fluctuation in the numbers and not the beginning of a trend.

### **4. Use the data**

- Be cautious of, but don't be scared off by the limitations of the data: use it.

### **5. Look for consistencies between different sources of information**

- Results are more believable if they are supported by multiple sources.

### **6. Mode of Exposure and Risk Behaviors**

- Don't confuse *mode of exposure* and *risk behavior* (See Glossary in the Appendix of commonly used epidemiologic terms).

#### **7. Risk Behavior and HIV Prevalence**

- Be careful about defining the *potential* for spread of infection versus the *presence of HIV* in that population. It takes both.

#### **8. Case Reporting**

- Are you looking at cases by *year of diagnosis* or *year of report*?

#### **9. Measures**

- Are you looking at a *rate*, a *count* or a *percentage*?
- Are you looking at *incidence* or *prevalence*?

## Description of Data Sources

HIV/AIDS case surveillance is the primary source of data presented in this report, but it provides only a partial view of the HIV/AIDS epidemic. Other sources of data are also included to obtain a fuller picture of the current HIV/AIDS epidemic. Each data source presented in the report is described below.

**AIDS Case Data:** These data are collected by the MDPH Bureau of Communicable Disease Control HIV/AIDS Surveillance Program. AIDS has been a reportable condition in Massachusetts since 1983. Data are collected statewide from all licensed healthcare providers, who are required by law to report CDC-defined AIDS cases to the MDPH HIV/AIDS Surveillance Program. Reports received directly from health care providers (*passive AIDS surveillance*) account for the majority of AIDS cases reported in Massachusetts. The other method of AIDS case retrieval, *active surveillance*, relies on the use of case-finding tools such as database matches, death certificate reviews, and CD4 lab reports which lead to identifying cases otherwise not reported. This method accounts for a small but growing number of cases. Information collected includes gender, date of birth, country of birth, race/ethnicity, locality, laboratory and clinical information, and risk defined by category and assigned according to a hierarchy of what is thought to be the most likely source of infection when multiple potential sources are reported. Though the AIDS data are a dynamic data set which is continually updated, most cases are reported within 6 months of diagnosis; 2001 is the most recent year for which data are available.

**Census Data:** These data are collected by the US Census Bureau. Information is collected from each US state and territory, which includes gender, race/ethnicity, age, education and earnings, insurance, employment and housing. Data from the most recent (2000) census are used when available, otherwise data are from the 1990 census where indicated.

**HIV Case Data:** These data are collected by the MDPH Bureau of Communicable Disease Control HIV/AIDS Surveillance Program. The implementation of a non-name based surveillance system for HIV reporting was initiated by the MDPH in January 1999. These data are submitted by licensed healthcare providers who are required to report HIV cases to the MDPH HIV/AIDS Surveillance Program. Information collected includes gender, date of birth, country of birth, race/ethnicity, locality, laboratory and clinical information, and risk defined by category and assigned according to a hierarchy of what is thought to be the most likely source of infection when multiple potential sources are reported. Though the HIV data are a dynamic data set which is continually updated, most cases are reported within 6 months of diagnosis; 2001 is the most recent year for which data are available. The system is being evaluated as a model for surveillance not using personal identifiers. Preliminary evidence suggests that the non-name system is working well with effective prevention of duplicate reports, good sensitivity and specificity, and completeness of data similar to name-based systems.

**HIV Counseling and Testing Data:** These data are collected by the MDPH HIV/AIDS

Bureau from MDPH-funded HIV counseling and testing (C&T) sites in Massachusetts. Since these sites provide approximately 30% of all C&T activity in Massachusetts, analysis of these data cannot be generalized to the entire Commonwealth. Information collected includes race/ethnicity, CDC-defined risk, reason for visit (partner notification, prenatal, etc.), and behavioral data, including unprotected sex in the past 6 months, and injection drug related risks. The most current complete year for these data is 2001.

**Massachusetts Behavioral Risk Factor Data (BRFSS):** These data are collected by the MDPH Bureau of Health Statistics, Research and Evaluation. These data are collected through the BRFSS, a comprehensive self-report survey on a full range of health influencing behaviors to Massachusetts adults via a random digit dialing sampling methodology. In recent years approximately 5,000 –7,000 interviews have been conducted, including an over-sampling of minority residents and residents of the largest cities in Massachusetts. Information collected includes gender, race/ethnicity, age, locality, and behavioral data including HIV related risks. The most current complete year for these data is 2001.

**Pediatric Spectrum of Disease (PSD) Data:** These data are collected by the Pediatric Spectrum of Disease (PSD) study administered through the New England Regional Newborn Screening Program, University of Massachusetts Medical School. This study has been supported by the National Institutes of Health and then the Centers for Disease Control and Prevention since 1989. Data are collected from seven pediatric referral hospitals through medical record review by nurse data abstractors who work for the individual hospitals. The nurse assigns a patient code number to each case to ensure the anonymity of information collected and abstracts the data every six months onto standardized forms designed for this study by the CDC. All HIV-infected and known perinatally exposed children are enrolled at birth or when HIV infection in the child is diagnosed.

**Sexually Transmitted Disease (STD) Case Data:** These data are collected by the MDPH Division of STD Prevention of the Bureau of Communicable Disease Control. These data are collected statewide from health care providers, who are required by law to report nine STDs, including syphilis, gonorrhea, chlamydia, and chancroid. Collection bias exists for some STDs, such as chlamydia, where screening of asymptomatic persons is done much more frequently in women than in men. Also, the personal nature of STD data may affect providers' willingness to report. The STD Division has promoted laboratory reporting as an adjunct to provider reporting to diminish bias. STD data is included because it indicates a level of risky sexual behavior. Unprotected sex, especially in a context where HIV prevalence is substantial, raises the likelihood of becoming HIV infected. Information collected includes gender, age, race/ethnicity, locality, infectious agent and clinical characterization of the infection. The most current complete year for these data is 2001.

**Unlinked HIV Seroprevalence Data:** These data are collected by the MDPH Bureau of Laboratory Sciences. Data are collected from three selected STD clinics located in urban areas of Massachusetts. HIV seroprevalence studies have been conducted by the

MDPH since 1988. Information is collected in a way that preserves anonymity but allows analysis by gender, race/ethnicity, age group, and some co-infections. The most current complete year for these data is 2001.



## Summary of Strengths and Limitations of Data Used in the Epidemiologic Profile

Source of Information	Description	Strengths	Limitations
AIDS Case Data	<ul style="list-style-type: none"> <li>Collected by MDPH Bureau of Communicable Disease Control HIV/AIDS Surveillance Program</li> <li>Reportable condition since 1983</li> <li>Reportable statewide</li> <li>All licensed healthcare providers are required by law to report</li> </ul>	<ul style="list-style-type: none"> <li>Statewide reporting, population based</li> <li>Risk information is available</li> <li>Completeness of reporting is high</li> <li>Comparable with other states</li> </ul>	<ul style="list-style-type: none"> <li>Under-reporting (10% -15%) hampers interpretation of AIDS case data</li> <li>Not all cases are reported at time of diagnosis (reporting lag)</li> </ul>
Census Data	<ul style="list-style-type: none"> <li>Collected by the US Census Bureau</li> </ul>	<ul style="list-style-type: none"> <li>Collected nationwide</li> </ul>	<ul style="list-style-type: none"> <li>Only updated in 10 year intervals</li> </ul>
HIV Counseling and Testing Data	<ul style="list-style-type: none"> <li>Collected by MDPH HIV/AIDS Bureau</li> <li>Collected at all MDPH-funded counseling and testing (C&amp;T) sites in Massachusetts</li> </ul>	<ul style="list-style-type: none"> <li>Provides behavioral risk information</li> </ul>	<ul style="list-style-type: none"> <li>Since these sites only see about 30% of all HIV counseling and testing activity in Massachusetts, analysis of these data cannot be generalized to the entire state</li> <li>The type of client utilizing a publicly-funded counseling and testing site may not be typical of people at risk for HIV across the Commonwealth</li> </ul>



<b>Source of Information</b>	<b>Description</b>	<b>Strengths</b>	<b>Limitations</b>
HIV Case Data	<ul style="list-style-type: none"> <li>Collected by MDPH Bureau of Communicable Disease Control HIV/AIDS Surveillance Program</li> <li>Reportable condition since January, 1999</li> <li>Reportable statewide</li> <li>All healthcare providers are required by law to report</li> </ul>	<ul style="list-style-type: none"> <li>Statewide reporting, population based</li> <li>Risk information is available</li> <li>Comparable with other states</li> <li>Focus on alive cases presents a more current picture of the epidemic than AIDS data</li> </ul>	<ul style="list-style-type: none"> <li>May be incomplete because many infected people may not have been tested, or may know their status but have not yet entered care</li> <li>Non-named data set has limitations regarding matches with other data sets and case follow-up</li> <li>Code is not comparable with most other states</li> </ul>
Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) Data	<ul style="list-style-type: none"> <li>Collected by the Bureau of Health Statistics, Research and Evaluation</li> <li>A comprehensive self-report survey on a full range of health influencing behaviors of Massachusetts adults via a random digit dialing sampling methodology</li> </ul>	<ul style="list-style-type: none"> <li>Provides a random sample of the population</li> <li>Provides confidentially collected, behavioral risk information</li> </ul>	<ul style="list-style-type: none"> <li>Not all potential participants live in households with a phone</li> <li>Not all individuals with phones will agree to be interviewed</li> <li>Survey is long and requires extensive time to complete</li> <li>Surveys general population and does not necessarily capture those at high risk</li> <li>Survey available in limited number of languages (English &amp; Spanish)</li> <li>Data are self reported and not verified by medical records</li> </ul>
Pediatric Spectrum of Disease Project Data	<ul style="list-style-type: none"> <li>Collected by the Pediatric Spectrum of Disease Project</li> </ul>	<ul style="list-style-type: none"> <li>Longitudinal study continuous since 1989</li> <li>One of 7 PSD study sites in nation</li> <li>Completeness of data</li> </ul>	<ul style="list-style-type: none"> <li>Uninfected children of HIV-infected mothers may never be enrolled</li> <li>Reporting lag</li> </ul>

Source of Information	Description	Strengths	Limitations
Sexually Transmitted Disease (STD) Case Data	<ul style="list-style-type: none"> <li>Collected by MDPH Bureau of Communicable Disease Control Division of STD Prevention</li> <li>All providers are required by law to report nine STDs, which includes syphilis, gonorrhea, chlamydia, and chancroid</li> </ul>	<ul style="list-style-type: none"> <li>Statewide reporting, population based</li> </ul>	<ul style="list-style-type: none"> <li>Risk information is not reported</li> <li>Willingness of provider to report affected by the sensitive nature of STDs</li> <li>Reports are not received from those not seeking care</li> <li>Bias is introduced for some STDs, such as chlamydia, where screening of asymptomatic persons is done much more frequently in women than in men</li> </ul>
Unlinked HIV Seroprevalence Data	<ul style="list-style-type: none"> <li>Collected by MDPH Bureau of Laboratory Sciences</li> </ul>	<ul style="list-style-type: none"> <li>Gives a part of the demographic picture of HIV prevalence</li> <li>Stringent methodology</li> </ul>	<ul style="list-style-type: none"> <li>Limited to time of testing</li> <li>Limited demographic information</li> <li>Limited to clinic or treatment populations</li> <li>Not representative of the general population</li> </ul>